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The 21st UK Renal Registry Annual Report: a summary of analyses of paediatric data in 2017

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Short title: Summary of the 21st UKRR Annual Report – paediatric data

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Introduction

Children with end-stage kidney disease (ESKD) requiring renal replacement therapy (RRT) are usually managed in one of the 13 paediatric nephrology centres in the UK. The UK Renal Registry (UKRR) collects, analyses and reports data on children receiving RRT in these centres.

The UKRR annual report presents analyses relating to the attainment of The Renal Association audit measures (1), national averages to enable benchmarking and long term trends for children on RRT for ESKD. Data are reported by centre to enable between centre comparisons.

To improve the timeliness of data reporting, the format of the UKRR 21st Annual Report, which included data to 31 December 2017 (2), differs significantly to that of previous years. For paediatric data, changes include a single chapter reporting demographic and biochemical data, reduced clinical commentary, a higher threshold for data quality control (with data completeness at least 70%) and greater alignment of analyses to The Renal Association guidelines (1).

In this article, we summarise the analyses of paediatric data presented in the UKRR 21st Annual Report. The corresponding adult summary is published separately in this issue. The full UKRR 21st Annual Report can be accessed at https://www.renalreg.org/reports/data_to_end_2017/.

Materials and Methods

The paediatric data chapter of the UKRR 21st Annual report describes children aged less than 18 years of age with ESKD who were on RRT in the UK for at least 90 days in 2017 under the care of paediatric renal centres. Children with ESKD are managed within a paediatric centre until transition to an adult centre, which occurs in general between 16 and 18 years of age. Young people aged 16 to 18 years may therefore be managed in either paediatric or adult services. This varies across the UK and is dependent on many factors, including local practices, social factors and child/family wishes. Consequently, demographic data have focused on children aged less than 16 years, because this represents a more complete cohort, whereas attainment of The Renal Association guidelines is reported for children aged less than 18 years managed in paediatric centres.

All 13 paediatric nephrology centres in the UK contribute data to the UKRR. As in previous years, data items were collected from centres via secure spreadsheets from the renal centre IT systems before being checked, validated and loaded onto the UKRR paediatric database. Data linkages with NHS Blood and Transplant have enabled audit reporting for children with a functioning kidney transplant.

The incident cohort was children new to RRT for ESKD in 2017, while the prevalent cohort was all children on RRT for ESKD for at least 90 days at the end of 2017.

As with adult chapters, the paediatric chapter was split into four sections. First, an introduction, which included a diagrammatic explanation of the paediatric cohort (figure 1). Second, the rationale for analyses, which was based primarily on The Renal Association guidelines (1). Third, a short list of key findings and fourth the analyses, which comprised tables and figures.

Insert figure 1 here

For the paediatric cohort, we report body mass index (BMI) by modality and the prevalence of cardiovascular risk factors (CVRFs): hypercholesterolaemia, overweight/obesity and hypertension. BMI is analysed using height-age z-scores and is categorised according to sex: females with a z-score of greater than or equal to 1.19 and males with a z-score of greater than or equal to 1.30 are classified as overweight/obese. Hypercholesterolaemia is defined using serum cholesterol or triglycerides values. A cholesterol level of greater than 5.2 mmol/L is classified as high; if cholesterol values are not available, a triglycerides level of greater than 1.13 mmol/L in children aged less than 9 years or greater than 1.46 mmol/L if aged 9 years or more is used. More details about the methods underlying the UKRR 21st Annual Report can be accessed in appendix A at https://www.renalreg.org/wp-content/uploads/2019/05/21st_UKRR_Annual_Report_AppA.pdf

Results

In 2017, 99 children (67.7% male) aged less than 16 years and with a median age of 7.6 years (interquartile range (IQR) 2.6–12.6 years) started RRT for ESKD, compared with 112 children the previous year. This gave an incidence of 7.9 per million age related population (pmarp). No trend has been noted in the number of children starting RRT for ESKD in the UK, with annual incidence rate ranging from 7.9–10.2 per million age related population (pmarp) over the past 5 years. For incident children in 2017, 42.4% started RRT on peritoneal dialysis (PD), 35.4% on haemodialysis (HD) and 22.2% received a pre-emptive kidney transplant. A fifth of incident children (20.2%) in 2017 were late presenters, starting RRT within 90 days of first nephrology review.

When incident data were examined by time period, greater proportions of non-White children (31.5%) and those aged less than 4 years (23.3%) were noted in the most recent 5 year period (2013–2017) than previously. Congenital anomalies of the kidneys and urinary tract (CAKUT) accounted for almost half of all incident cases of RRT in children: this proportion has been stable over time. In 2013–2017, an increase in the proportion of children with miscellaneous kidney disorders was noted, contributing 13.3% of incident cases. Over the past 15 years, there have been

increases in the proportion of children using HD as their first RRT modality: 2013–2017 was the first time period where HD use at RRT start surpassed that of PD. Live donor pre-emptive kidney transplantation has remained stable, while the proportion of children who received a deceased pre-emptive donor kidney transplant has fallen.

Insert figure 2 here

Excluding children aged less than 3 months and late presenting children (presenting to specialist kidney services within 90 days of RRT start), 33.8% (n=420) of incident children aged less than 16 years between 2003 and 2017 received a pre-emptive kidney transplant. Few Black (11.1%) or South Asian (23.1%) children received pre-emptive transplants, as did children aged less than two years (4.4%) or those who were diagnosed with a glomerular disease (7.3%).

As of 31 December 2017, 810 children aged less than 16 years (966 under 18 years) were receiving RRT for ESKD in one of the 13 dedicated paediatric nephrology units. Of this group, 522 (64.4%) were male and 555 (69.0%) were White. Most children (76.3%) had a functioning transplant (45.1% live, 31.2% deceased donor), with 13.1% on HD and 10.6% on PD. Of the 96 young people who transitioned to adult services, 84.4% had a functioning kidney transplant. Over time, increasing prevalence in children is noted: from 52.8 pmarp in 2013 to 64.8 pmarp in 2017.

Using z-scores standardised to the general UK childhood population, poorer growth, both in terms of height and weight attainment, was seen for children requiring RRT. This was more pronounced for prevalent children on dialysis compared to those with a functioning transplant. Prevalent children on dialysis had a median height z-score of -1.9 (IQR -2.95–-0.9) compared with -1.1 for those with a functioning transplant (IQR -2.09–-0.3). The median weight z-score for children on dialysis was -1.1 (IQR -2.13–-0.4) compared with -0.1 (IQR -1.16–0.8) for those with a functioning transplant. All centres had IQRs for height and weight that spanned the UK median.

The prevalence of cardiovascular risk factors (CVRF) collated by the UKRR was reported: this included body mass index (BMI), total cholesterol and systolic and diastolic blood pressure measurements. Analysis of these data was restricted to the 553 of 966 (57.2%) children aged less than 18 years with data for all 3 risk factors, a similar proportion compared with the previous year (57.4%). Of those with complete data, over a quarter of children (28.6%) had no recorded CVRF, 37.2% had 1 CVRF, and 34.2% had 2 or more CVRFs. This year, the prevalence of hypercholesterolaemia was similar to high BMI, affecting 37.8% and 37.5% of children, respectively.

As of 31 December 2017, the median systolic blood pressure (SBP) z-score reported for prevalent children on dialysis was 1.0 (IQR 0.19–2.1) and 0.4 (IQR -0.24–1.0) for transplanted children. An SBP

target of less than the 90th percentile was achieved by 53.3%, 60.0% and 82.9% of HD, PD and transplanted children, respectively. For diastolic blood pressure the same target was achieved in 55.6%, 66.7% and 76.5% of HD, PD and transplanted children, respectively.

This year's report focused on reporting estimated glomerular filtration rate (eGFR) using the Schwartz calculation (3) for transplant recipients, as opposed to creatinine values. The median eGFR for children with a functioning transplant (n=749) was 60 mL/min/1.73m^2 (IQR 48–76 mL/min/1.73m^2); the proportion of transplanted children with an eGFR of less than 30 mL/min/1.73m^2 varied across centres and ranged from 0–13.9%. Median eGFR was also reported by age and time since transplant for children with available data. Younger children tended to have higher median eGFRs at any given time point: overall median eGFRs were 85 mL/min/1.73m^2 (IQR 62–105 mL/min/1.73m^2) in children aged less than 5 years compared with 52 mL/min/1.73m^2 (IQR 39–66 mL/min/1.73m^2) in 16 to 18 year olds. At 1 year post-transplant, the median eGFR was 84 mL/min/1.73m^2 (IQR 54–97 mL/min/1.73m^2) for children aged less than 5 years, 69 mL/min/1.73m^2 (IQR 56–82 mL/min/1.73m^2) for 5 to less than 12 year olds, 63 mL/min/1.73m^2 (IQR 52–73 mL/min/1.73m^2) for 12 to less than 16 year olds and 53 mL/min/1.73m^2 (IQR 52–66 mL/min/1.73m^2) for 16 to less than 18 year olds. Declines in eGFR were noted with time across all age groups: between 1 and 5 years post-transplant, smaller percentage losses in eGFR were noted in older compared with younger children.

Attainment of biochemical parameters was reported for prevalent children on dialysis (n=217) and transplanted children with an eGFR of <30 mL/min/1.73m^2 (n=46). In general, a smaller proportion of dialysed children achieved the standards set compared with those who had a transplant: haemoglobin, calcium, phosphate and parathyroid hormone target ranges were achieved in 43.9%, 75.2%, 49.1% and 36.3%, respectively, of dialysed children, compared with 47.8%, 95.7%, 77.8% and 70.6%, respectively, of transplanted children. For bicarbonate values, similar proportions of dialysed and transplanted children achieved the set target: 75.2% compared with 73.9%.

A survival analysis in this year's report included 1,575 children aged less than 16 years between 2003 and 2016 with at least 1 year of follow-up: this showed a total of 84 deaths. As in previous years, younger children had the worst survival, with 88.5% (95% confidence interval 84.0–91.9%) alive at 3 years, compared with 97.5% in the 12 to less than 16 years age group (95% confidence interval 94.9–98.8%).

Insert figure 3 here

Conclusion and future analyses

This year's paediatric chapter focused on reporting key demographic and biochemical variables with good completeness for children receiving RRT for ESKD in the UK. We are grateful for the ongoing efforts of paediatric centres to submit data to the UKRR in a timely fashion, which enables thorough data checks and validation prior to publication. The UKRR is keen to expand upon data reported from the core paediatric dataset and is working with the Renal Association Clinical Services Committee to identify priorities for data collection, audit and research. Dependent on data completeness, areas of interest for inclusion in future reports include reporting data for all young people aged 16 to 18 years, irrespective of paediatric or adult management, as well as data for children with stages 4 and 5 CKD (non-RRT).

Author contributions statement

All authors made a substantial contribution to the content included in this summary; participated in drafting and critically revising the summary; approved the final version to be published; and agreed to be accountable for all aspects of the work.

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The UKRR would like to thank patients for the inclusion of their data and renal centres for submitting the data. The UKRR is grateful to NHS Blood and Transplant for sharing data.

Statement of ethics

The 21st UKRR Annual Report was produced in accordance with the provisions and regulations of the government of the United Kingdom and Northern Ireland, the National Health Service in England, Northern Ireland, Scotland and Wales, the Information Commissioner's Office, and where applicable the devolved governments of Northern Ireland, Scotland and Wales. Due to the number of patients whose data are included in the annual report, the UKRR relies on provisions under health and social care legislation (both British and devolved) which nullify the requirement for common law consent to be collected for audit purposes.

Disclosure statement

The authors have no conflicts of interest to declare.

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Figure legends

Fig. 1. An example of a patient cohort diagram used in the 21st UKRR Annual Report – pathways paediatric patients could follow to be included in the UK 2017 incident and/or prevalent RRT populations

Fig. 2. Start RRT modality for paediatric patients (less than 16 years old) incident to RRT by 5 year time period

Fig. 3. Unadjusted Kaplan-Meier survival (from day 90) of incident paediatric RRT patients (less than 16 years old) between 2003 and 2016 by age group at start of RRT